

"Genetic counseling is a critically important component of the appropriate use and integration of genetic tests and services"

Report of the Secretary's Advisory Committee on Genetics, Health, and Society. 2006



Genetic Counselors

Uniquely qualified and solely dedicated to providing competent genetic counseling services¹

Genetic counselors are health care providers uniquely trained in Master's degree programs to provide quality genetic counseling services. Genetic counselors are certified by the American Board of Genetic Counseling.

In health care settings, genetic counselors are tasked with:

- Eliciting and interpreting medical and family histories.
- Calculating the risk of occurrence or recurrence of a genetic condition.
- Imparting clear, accurate and comprehensive information regarding medical conditions with a genetic component, including risks, symptoms, screening and treatment options as well as testing options to patients and healthcare providers.
- Providing psychosocial support to individuals and families coping with a genetic condition.

Genetic counselors work closely with individuals and families to:

- Determine the appropriateness of pursuing genetic technologies.
- Facilitate informed decision-making.
- Communicate with the family, laboratories and other healthcare providers.
- Promote screening and preventative care to minimize health risks.

Genetic counselors:

- Recognize and respond to ethical and moral dilemmas.
- Identify factors that promote or hinder client autonomy.
- Understand issues surrounding privacy, informed consent, confidentiality, and real or potential discrimination.

Each year, thousands of Michigan residents benefit from the services provided by genetic counselors.

- 1 in every 20 babies is born with a birth defect³
- 20-30% of all infant deaths is due to genetic disorders⁴
- 1 in every 9 pediatric hospital admissions is for a child with genetic disorder⁵
- 1 in every 8 adult hospital admissions is for a genetic cause⁶
- 50% of intellectual disability has a genetic basis⁷
- 15% of all cancer has an inherited susceptibility⁸
- 10% of chronic disease (heart, diabetes, arthritis) has a significant genetic component⁹

Genetic counselors work in various health care settings in Michigan, including universities, industry, public and private health care settings.

Areas of practice include:

- Pediatric Genetics
- Cancer Genetics
- Neurogenetics
- Reproductive Genetics
- Infertility Clinics
- Other specialty Clinics

To find a genetic counselor, go to www.nsgc.org or www.abgc.net.

To view the centers where genetic counselors work, visit www.migeneticsconnection.org.

Now is the Time to License Michigan Genetic Counselors

Genetic Counselor Licensure will provide Michigan citizens:

- **Protection from harm of receiving inaccurate information about genetic risks from individuals who do not meet minimum education and certification standards.**
 - Numerous cases of physical, psychological, or financial harm due to the inappropriate use or interpretation of genetic information in Michigan have been described.¹
 - Errors in care may be inevitable, but regulating providers through competency guidelines should reduce the frequency.
 - Approximately 30% of non-genetics health care providers misinterpret the results of genetic tests that they order on their patients.² These errors in interpretation can have a significant impact on patients and their family members.
- **Cost savings of healthcare dollars via accurate testing on appropriate individuals.**
 - Healthcare providers without training in genetics often order more expensive genetic testing than is indicated, amounting to unnecessary health care expenditures.³
- **Assurance that minimum education, continuing education, and certification standards have been met by individuals using the title of genetic counselor.**
 - Genetic counselors hold advanced degrees and are uniquely trained to provide their services.
 - The public and some healthcare providers are generally unaware of the minimal standards for formally trained genetic counselors. In fact, patients report receiving services from what they originally believed to be genetics experts, when in fact the providers of these services had very limited, if any, formal genetics training.
 - The growing availability of direct-to-consumer genetic testing makes the urgency of ensuring the availability and recognition of quality genetic counseling services to patients in Michigan even greater.⁴
 - Human genetics is advancing rapidly, making continuing education critical. In 2014, genetic testing is available for over 4,400 diseases, an increase of over 3,000 diseases over the last 10 years. In the absence of regulation, compliance for important continuing education may be deficient since adherence to professional recommendations is otherwise voluntary and not required to work as a genetic counselor.
- **Reassurance that the quality of care in the state of Michigan is comparable to that of neighboring states.**
 - Some of our nearest neighbors, Ohio, Illinois, Indiana, and Pennsylvania have enacted laws for genetic counseling licensure. Ohio and Wisconsin are actively pursuing similar legislation.
 - Without licensure, individuals without the appropriate credentials could provide genetic counseling and therefore decrease the quality of the service in Michigan as compared to neighboring states with regulation.
- **A mechanism to report, investigate, and sanction claims of incompetent, unethical, and/or unlawful behavior of a genetic counselor.**
 - In the absence of regulation, there are no professional consequences for practicing outside of defined guidelines. Without regulation, incompetent genetic counselors can continue practicing, leaving families in Michigan vulnerable.
- **Guarantee that the state is working to train and retain highly educated health care professionals.**
 - The state of Michigan is home to two graduate training programs in genetic counseling. Graduates of these programs are in high demand and consider the availability of licensure in a state when seeking employment.

References:

1. Brierley K, et al. Errors in Delivery of Cancer Genetics Services: Implications for Practice. *Conn Medicine*. 2010;74(7):413-425.
2. Giardiello FM, et al. The use of interpretation of commercial APC gene testing for familial adenomatous polyposis. *NEJM*. 1997;336(12):823-7.
3. Plon SE, et al. Genetic testing and cancer risk management recommendations by physicians for at-risk relatives. *Genet Med*. 2011;13(2):148-54.
4. U.S. Government Accountability Office (GAO). GAO-10-847T. <http://www.gao.gov/products/GAO-10-847T>. Updated July 22, 2010.



***Genetic counselors are the health professionals specifically trained to address
the complex issues associated with genetic disease.***
